

Statement on Ethical & Transparent use of Funds Raised by Cystinosis Foundation Ireland"

In light of recent revelations concerning the inappropriate and unethical use of funds raised by certain charity and support organisations in Ireland, we at Cystinosis Foundation Ireland wish to reiterate our work and how we use funds raised from the public.

Cystinosis Foundation Ireland exists solely to support people with the condition and their families. We do this by funding medical research with the aim of better understanding the condition, improving existing treatments and hopefully one day the discovery of a cure.

Cystinosis Foundation Ireland does not employ or remunerate any staff and is wholly run by volunteers. Our Foundation has no overheads such as staff costs, fundraising commissions, rental of premises, office furniture or equipment. This ensures that all funds raised go into clinical research of cystinosis. All research undertaken is done by working with Ireland's Health Research Board and projects are only selected once approved by a panel of experts and the Board of Cystinosis Foundation Ireland.

A detailed listing of all funds raised and used is presented in our Audited Financial Statements, available in the "Who are we" section of our website. For further details, please contact us directly at mail@cystinosis.ie.

We would like to take this opportunity to thank all those who have supported cystinosis research in the past, we urge you to continue in your support and we wish to assure everyone that we are committed to the highest ethical and transparency standards.